



## **Genetic Disease Program Hemophilia – Fact Sheet**

The result of not funding this activity will continue to force hemophilia patients in crisis to access emergency room treatment for pain management.

### **Objective**

To ensure that patients with coagulation disorders receive optimum medical care and supportive services of the highest quality in all areas of the state of Louisiana

### **Performance Indicators**

1. Ensure that all patients with coagulation disorders receive appropriate case management
2. Assess the quality of care to patients with coagulation disorders through quarterly meetings

### **Narrative**

The Office of Public Health contracts with the Louisiana Comprehensive Hemophilia Center at Tulane Medical School (Hemophilia Center) to provide medical examinations & consultations, patient education, and specialized nursing services with individuals affected with coagulations disorders in Louisiana. The Louisiana Comprehensive Hemophilia Care Center diagnoses, evaluates and treats patients with congenital and acquired conditions of bleeding such as hemophilia, von Willebrand disease and other rare factor deficiencies. This specialized, multi-disciplinary clinic is open to all ages. Patients from Louisiana and the gulf coast region may be referred by their physician or may self-refer.

The Center is the only federally-funded hemophilia treatment center (HTC) in Louisiana and offers a comprehensive model of care which includes evaluation and treatment recommendations from hematology, nursing, physical therapy, social work, dental and orthopedic services. This approach has been proven to address health and emotional issues of patients with this chronic disease.

**Better Health**

This program optimizes a patient's ability to become more self-reliant and less reliant on institutional care as a result of better disease management. Better disease management also improves the quality of life of patients affected with coagulation disorders. This program also allows for better coordination between primary care physicians and specialists so that tests are not duplicated therefore driving down the cost of service. Patients are also taught how to handle or avoid bleeding episodes thus resulting in a decreased burden on emergency rooms.

**Safe & Thriving Children & Families**

This program allows families affected by hemophilia to become more self-sufficient. Poor access to disease management can result in increased days missed from school or work due to hospitalization as a result of bleeding episodes. Wrap around services with this program include education school personnel on how to handle a patient with a bleed.

This activity is supported by RS 40:1299.5. Poorly managed patients would end up costing the state significantly more as preventable symptoms would go on to become life threatening problems